

# “Our Cancer Journey”

## Reflections of Getting Heard clients and peer advocates receiving treatment in Oxfordshire

**A report by the Cancer, Older People and Advocacy (COPA)  
Volunteer Peer Advocate - Patient Experience Group**



**Compiled by  
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(Volunteer Peer Advocate and retired Registered General Nurse)**



*Patients included: Retired GP, Director of Healthcare, Registered General Nurse and Solicitor  
With thanks to everyone who contributed including carers*

## 1.) Background and methodology

In 2014 Getting Heard (formerly Oxfordshire Advocacy) was appointed by OPAAL (Older Peoples Advocacy Alliance) to provide peer advocacy services for older people in Oxfordshire impacted by cancer. This offering was part of a national programme of activity over 3 years in partnership with Macmillan and with funding from the Big Lottery.

The aim of this service is to empower older people to get their voices heard through their cancer journey. Our specially trained peer advocates, who themselves have been affected by cancer and have received Macmillan training, support their partners to access the services they need. This can include:

- **Preparing for and attending hospital appointments**  
The volunteer advocate may support partners to prepare and ask questions, take notes on the partner's behalf during appointments and reflect with their partner afterwards on what information they've been told
- **Exploring options and making informed choices**  
Spending time with partners to support them to identify the issues affecting them; exploring all available options and then making informed choices.
- **Accessing advisory services and other practical support**  
For example: providing support to make a call to the Macmillan helpline to get advice on finances, or to visit their bank if their financial circumstances have changed.

This report emerged from the volunteer peer advocates support group in which advocates could share and compare their own and their advocacy clients' experience of cancer services and draw out conclusions and recommendations. Our peer advocates had been working with their clients for varying periods depending on what the issues were. This can range from supporting someone in a one off meeting or appointment to working with the same client on a range of different issues over a period of many months – indeed our longest standing case goes back 2 years. This report particularly draws on the experience of supporting people through medical appointments and other hospital based processes, such as chemo or radio therapy.

The idea for this group emerged from Getting Heard's volunteer support group chaired by **Rosie Young, Registered General Nurse (Retired)**. The membership was open to all our peer advocates, but in the event the participants were the advocates who have been cancer patients themselves (rather than carers of other patients). Consultation initially took place by email and then a meeting was held at which discussion revolved around both the advocates own experience of cancer services and also that of their advocacy clients. From this the main themes emerged which led to the formulation of this report and engagement with Healthwatch.

What makes this report unique is the fact that the contributing advocates have also had their own experience of treatment. This underpins their advocacy role and gives them a broader understanding of what their partners are going through and how the hospital systems work.

The views and opinions expressed in this report are those of the members of the Patient Experience Group and their clients. Getting Heard is keen to ensure that the report is positioned as feedback and not criticism of a much valued service, and will ensure that local commissioners and providers will receive this report and are alerted to the recommendations that the Group has made in this report. Getting Heard is keen to work with providers to help implement any changes that may arise out of the recommendations made.

## 2) Findings and analysis

The main areas considered were:

- i) Practice around patient consent and access to information
- ii) Opportunities for practical improvements to be made in the written information provided by the Oxford University Hospitals NHS Foundation Trust to people accessing cancer services
- iii) People's overall experience of using the Churchill hospital to receive cancer treatment

Throughout the report quotes gathered from our cancer advocates and the people they support have been used to throw light on concerns raised and recommendations made.



### i) Patient Consent and Access to information

A common area of concern among volunteer peer advocates was the level of information given to patients to support their decision making process on treatment options. Peer advocates were concerned that in some cases patients didn't have sufficient information in respect of all the treatment options available, making it difficult for the patient to give informed consent for their treatment.

This concern was rooted in the peer advocates awareness of a relevant legal case in 2015 (Montgomery v Lanarkshire Health Board) in which the General Medical Council gave evidence that doctors has a professional and ethical duty to advise a patient of all their treatment options, the risks of each option and the benefits of the option, and it was then for the patient (not the doctor) to advise which option they wished to choose.

Peer advocates felt this case emphasised the need and value of advocacy, as advocates support patients to ask questions and raise concerns about their treatment options. This in turn enables doctors to discharge their duty to take reasonable care to ensure the patient is aware of any: potential benefits, risks, burdens, side effects of each treatment option, including the option to have no treatment and to make it clear that there is no pressure on the patient to accept advice.

In reflecting on the issue of consent the volunteer Peer Advocates identified the following issues:

**1. Patients may be given technical information without enough information and analysis of the pros and cons of each treatment option, including not having any treatment.**

*"I decided to have the biopsy which indicated the presence of cancer. At no stage was I advised to have this procedure". If this patient had not asked for the biopsy, it is likely his cancer would not have been staged and the appropriate treatment would not have been given.*

**2. There is often a sense of pressure to accept "Gold Standard" (i.e. the medical professions current view of best practice, without necessarily consulting the patient or explaining all the options to them).**

*"After an operation in my left lung for cancer I was diagnosed a year later with a primary in my right lung. I was under considerable pressure to have a particular treatment from the Clinical Fellow and Specialist Nurse despite having significant risk factors which would have impeded recovery. In consultation with my GP, Palliative Nurse and family I opted for a different course of treatment. The Specialist Nurse, when I told her (having submitted a risk assessment), contacted my Palliative Nurse to question my capacity to make a decision."*

**3. There may be a lack of clarity at the start of the process about the number of operations a particular course of treatment will require**

*"The number and extent of operations should be clearly spelt out. I was told that I would need a second operation for my agreed implant only as I was going to the theatre for my mastectomy. The implant later had to be removed in a third operation".*

**4. People receiving treatments may not always be given adequate information about the long term effects of operations i.e. nerve damage.**

*"I have gone from a sixty plus active person to needing a blue badge, upper limit attendance allowance with severe restrictions on my social life because of pain (associated with treatment given)".*

**5. People are not always given enough information about the long term side effects of treatment**

Doctors may sometimes fail to appreciate the importance for the patient of understanding the long term side effects and may not provide enough information about these. *"The long term effects of chemotherapy and radiotherapy should be clearly identified. I was never told about the lifelong problems to be encountered with radiotherapy, from which I am still suffering. Attitude of my oncologist dismissing treatment that is causing anaemia as of little consequence – putting in an email that he would ring me if he had time".*

**6. Patients may not be provided with enough information about the effectiveness of a particular course of drug therapy**

*"Medication, such as Anastrozole, should be discussed and the side effects clearly spelt out. I have just cancelled my last two years of Anastrozole due to side effects and having discovered, with some difficulty that the percentage risk increase of a recurrence of cancer is only 2%".*

To note: the above statements and others provided in this reflective paper, relate to particular aspects of our volunteer Peer Advocates' personal experiences of their cancer treatment. It is acknowledged that these may not be experiences which have been shared by/are common to all patients.

## ii) Written information

The volunteer Peer Advocates identified the following issues around the written information provided to people accessing cancer treatment:

### 1. Complex patient letters

Advocates found that the letters sent to patients from the consultant are often very detailed and complex and seem to be aimed at GPs and other medics in the team rather than the patient themselves. Advocates reflected that cancer patients particularly need written explanations of what is happening to them because cancer treatment is complex and consultations tend to be long and can be emotional, such that even the most focused person can lose concentration on what is being said.

As one advocate explained: *"In all my advocacy cases I have been asked to do a filing job on their medical letters. When I first meet the client just to try to get to grips with what is going on with their treatment and when their next appointment is. With a few exceptions patient follow up letters are full of technical information that is not easy to understand"*.

### 2. Appointment letters

Advocates reflected that the content of appointment letters can be over-whelming for their partners. Every letter that comes from Oxford University Hospitals NHS Foundation Trust confirming appointments and/or cancelling and amending appointments includes large volumes of routine paperwork with it such as information on car parking, maps of the hospital etc.

As a peer advocate explains: *"My advocacy clients are often overwhelmed with the paperwork they receive and often just open the letter and don't even read it because they get so mixed up with what is what"*.

### 3. Complex processes and treatment pathways can be hard for patients to keep track of

As one peer advocate shared: *"Every advocacy client I have worked with has not been able to tell me what drugs they are taking and who their consultant is or indeed the name of any doctor treating them. It often takes weeks for the copy of the diagnosis letter to reach them / their GP and that letter is often written in so much detail and with so much complexity that they simply cannot understand"*.

### 4. Leaflets specifically for cancer patients are not always available for patients when they are needed.

Booklets with valuable information that could be routinely available to patients to pick up are often not – this appears to be because the Churchill and Horton hospitals do not keep sufficient stocks.

## iii) Issues for people using the Churchill Hospital

### 1. Insufficient seating in the main waiting area

*"There is not enough seating in the waiting area outside the clinics. As a patient I often had to sit on the floor to wait and give up my seat for an older patient / older patient relative. Couples and relatives are often split up and "non-patients" are sent back to the main waiting area 100m away because of this.*

*In the main waiting area you have no idea what is going on in the clinic area and when your relative / friend is likely to be out of treatment. There is no phone signal and so you can't even keep in touch by text etc. if you have a mobile. This is causing untold extra stress for patients and just needs sorting out urgently."*

## **2. Disposal of partially emptied water cups**

*“There are lots of prostate cancer patients receiving radiotherapy as a first line treatment. They must have a full bladder and empty bowel for this treatment and must time this correctly. They therefore have to drink precise amounts of liquid as they wait for treatment.*

*There is nowhere to pour away water from cups that are unfinished when people drink from the water cooler. Therefore there are half empty cups of water everywhere on the floor and tables (compounded by the lack of seating issue). Can a drain / soakaway be installed in the waiting area?”*

## **3. Concerns with patient dignity when weighed in corridors**

*“In the Churchill outpatients and MRI/CT scanning areas and in the Churchill PET scanning areas your identity details are checked and you are weighed on scales that are in an open corridor with any number of people walking past. Can the scales be moved to a more private area?”*

## **4. Scope for improvements to the prosthesis room**

A number of Advocates reflected on their experience of the prosthesis room and wondered if there could be scope to make some improvements to provisions in the room:

*“The Churchill prosthesis / bra fitting “clinic” post mastectomy is grim. It is a very small enclosed room with not enough space to turnaround, let alone try on a bra / prosthesis. The amount of stock they can carry is absolutely minimal as well because they have no storage space and so you are lucky if you have one bra in your size (and they all seem to have been made/styled in the eastern bloc in the 1970s and are just utterly depressing).*

*Can this service be revamped and somehow use the expertise of an outside firm to run this? e.g. bring in one of the local lingerie firms that does this such as Pure Marie in Abingdon or work through a shop in the Churchill concourse such as the ladies fashion shop or the wig / hat shop or bring in a specialist supplier such as Anita? It is devastating to lose your breast(s), and even more soul destroying to have to use this service”.*

## **5. Car parking at the Churchill**

Advocates recognised that car parking is an issue for many hospitals and noted the particular impact it can have on those having cancer treatment:

*“Cancer treatment involves lots and lots of appointments and trips to the Churchill (some of them such as some types of radiotherapy or PET scans are actually time critical). Treatment trips are often when you are feeling shattered, depressed, vulnerable and physically sick or needing to make a dash for the toilet.*

*Car parking issues can cause you to be late or miss key treatment and consultant appointments or even worse not make it to the toilet in time. It is no wonder that I have seen many patients / patients relatives in tears in the Churchill (and it has happened to me too) because they are so upset and stressed because of problems with car parking.”*

### 3.) Recommendations

Based on the findings detailed above, the Peer Advocates identified the following recommendations:

#### i.) **Health care professionals to be provided with additional training to further support them to:**

- Present the pros/cons of all treatment options including having no treatment in an accessible way given the requirement for informed consent,
- Ensure patients do not feel pressurised to accept the “gold standard treatment” and that other treatment options are also presented
- Are clear about the number of operations patients may need
- Provide enough information about the possible long term side effects of treatment options
- Provide information on the efficacy of treatment courses
- To avoid the risk of overloading patients with technical information

To ensure these changes are embedded into health culture, it is recommended that these changes be reviewed within the supervision and appraisal system among staff teams.

#### ii.) **Recommendations around provision of written information**

- Instigate a diagnosis treatment and professional team summary card
- All patients to be given a simple card at their diagnosis appointment that they keep with them at all times. That card should clearly say what type of cancer they have, the names (generic and brand names) of all the drugs they are taking and the name of their consultant oncologist.
- Ensure that consultant letters summarising the situation are accessible to both patients and their GPs and are therefore written in an appropriate style; clear and with minimal-technical language.
- All the accompanying information provided to people with their appointment letter to be given once at the outset of treatment to make it more accessible and less intimidating for people.
- Oxford University Hospitals NHS Foundation Trust and Primary Care Commissioners to produce a specific leaflet on “where to go for information about cancer treatment and support for cancer patients and their families in Oxfordshire” that should be given to every patient at the point that they get a cancer diagnosis

In addition volunteer Peer Advocates noted the value of tailoring information to the right stage in the cancer patient’s treatment. On this basis they felt it important to recommend the following MacMillan publications as standard, which have been found to be particularly helpful at the diagnosis phase of cancer:

- How are you feeling? The emotional effects of cancer (MAC11593)
- Making treatment decisions (MAC12163)
- No one overlooked- experiences of older people affected by cancer (MAC15365\_OLDER)
- Planning your support and care: Having a holistic needs assessment. (MAC12957)
- The Cancer Guide (MAC5765)

**iii.) Recommendations for improvements to the main waiting area at the Churchill Hospital**

- More seating to be provided in the waiting area
- Installation of a drain / soakaway be installed in the waiting area to address the issue with discarded cups by water cooler that are partially filled with water
- Re-siting of weighing scales to a more private space to respect people's dignity
- Improvements to prosthesis room potentially in partnership with a local lingerie firm.
- Improvements to parking arrangements to reduce waiting times for available space.

**4.) Appendix: supporting statements from peer advocates**

**i.) Doctors letters**

*Doctors letter to GPs and patients are almost always very detailed and very complex and seem aimed at GPs and other medics in the team rather than the patient themselves. Cancer patients particularly need written explanations of what is happening to them a) because cancer treatment is particular complex and consultations tend to be long and b) because consultations are often very emotional / difficult and even the most together person can lose concentration on what is being said. Is there any way that a "best practice" example patient letter can be produced to upskill and educate the medics in what works for patients (and what doesn't work)?*

**ii.) Appointment letters**

*It seems that every letter that comes out from the OUH confirming appointments and/or cancelling and amending appointments has a stack of other paperwork with it including information on car parking, maps of the hospital, how to comment on things and friends and family recommendations. Is there any way that the issue of appointment letters can be changed so that all the accompanying information is given once at the outset of treatment and then the appointment letter is reduced to one side of A4 only? After 2.5 years of treatment myself I have a lever arch file that is 10cm thick with all of my medical letters and related treatment paperwork.*

*In all my advocacy cases I have been asked to do a filing job on their medical letters when I first meet them just to try to get to grips with what is going on with their treatment and when their next appointment is. Improving the quality of communication and reducing the amount of actual paper is good all round – less trees are used, patients will find it easier to keep track of appointments & so will hopefully attend - reducing no shows. Patients are also empowered when they understand what is happening to them and can then make informed choices.*

**iii.) Oxfordshire "where to go for information" leaflet**

*OUH and Primary Care Commissioners to produce a specific leaflet on "where to go for information about cancer treatment and support for cancer patients and their families in Oxfordshire" to be given to every patient at the point that they get a cancer diagnosis. The leaflet should contain clear guidance on what support is available and where to go locally (Maggies, Hummingbird Centre Bicester etc.) and where to look on the internet safely for trusted, well worded, up to date information – for patients/relatives/friends who use the internet of course. The leaflet should signpost Macmillan and the good cancer specific charities such as Breast Cancer Care etc. It should also point out that researching information is something that OA can help with if needed.*

*The leaflet itself & links can also be made available online, however please note, when you have never used a computer, can hardly see with failing eyesight, are alone and isolated generally you are not going to get info on the internet yourself. You will need support to find it / download it,*



order it. Suggest that that leaflet could also signpost patients to useful Oxfordshire contacts for complementary treatment & advice as well – I have found the following are areas where I have made really useful contacts with local practitioners who have experience in working with people with cancer and their families: Nutrition advice, Counselling – clinical psychologist, Reflexology, Mindfulness, Pilates, Manual Lymphatic Drainage, Podiatry, Hairdressing & Nails.

**iv.) Macmillan Leaflets**

*I have found the following documents from Macmillan and Breast Cancer Care useful to my advocacy clients with breast cancer, particularly at the diagnosis stage. They all ask for information & find it universally helpful to understand and to be able to read at their own pace and also to show relatives etc. These booklets should be routinely available to patients to pick up but they are not – seemingly because the Churchill / Horton is not keeping stocks and instead expecting people to find their way to them.*

- Understanding breast cancer (MAC11616)
- Breast cancer and you: diagnosis, treatment and the future (BCC44)
- Letrozole (Femara) (BCC64)
- Understanding your pathology report (BCC161)
- Complementary therapies (BCC55)
- Your breast clinic appointment (BCC70)
- Invasive ductal breast cancer (BCC210)
- Invasive lobular breast cancer (BCC45)